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## Assisted & Independent Living: The User Perspective

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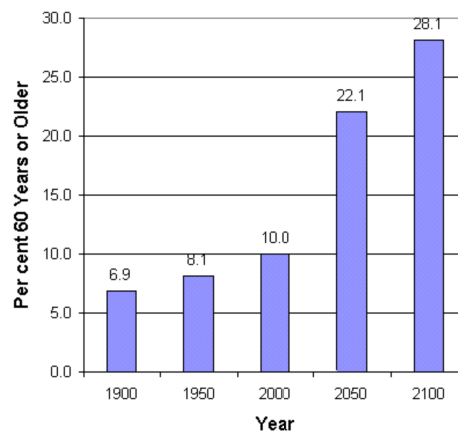
### Abstract

There is little doubt that the elderly population of the world is growing. The greatest growth in this segment of society happens to be in the industrialized nations and is becoming a serious public policy issue, which will have a dramatic economic impact. Many approaches to solving this problem have been presented from various perspectives. In the current work, we examine the challenges associated with the users of services for the elderly. While much of today's discussion centers on technologies and best practices, it is essential that the user be considered in any proposed solutions.

### Introduction

Statistics from the United Nations forecast that by the year 2100 [1], over 28% of the world's population will be of age sixty or above (see figure 1). These data are for all nations, industrialized and developing. Interestingly, the greatest growth of this portion of the population will take place in industrialized countries with the largest percentage in Europe. Currently Europe shows an elderly population of approximately twenty percent with a projected growth to the thirty five percent level by the year 2050.

Three Centuries of World Population Ageing



Source: Long-Range World Population Projections: Based on the 1998 Revision. The Population Division, Department of Economic and Social Affairs, United Nations Secretariat

Figure 1: World Population Aging

Of the top 40 industrialized nations of the world the countries with the largest percentage of populations over the age of 65 include Italy, Japan, Greece and Germany with the United States being 19<sup>th</sup> in this list (see figure 2). But these numbers do not reflect the dramatic change in these data in the next decade. In the United States, the so called “Boomer Generation” is now entering the 60 year old category and in not to many years the statistics will be quite different. The estimates project an elderly population of over 20% in the U.S. by the year 2030 [2].

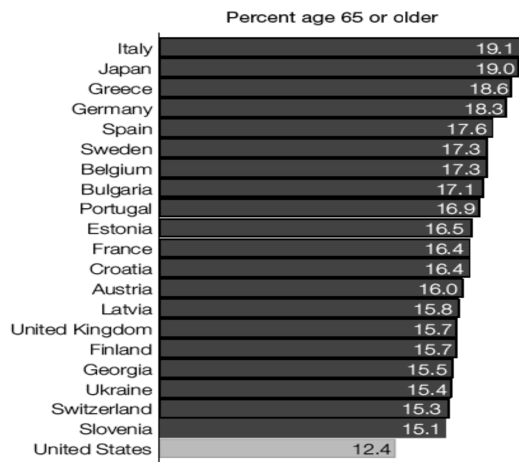


Figure 2: Elderly population in the industrialized world.

The bottom line presents the industrialized world with an interesting twist of fate. That of having a complex, and expensive problem associated with a rapidly growing portion of their population. A problem with an interesting, and difficult set of technical and societal issues. Many of the medical and technical issues are currently being addressed by numerous groups around the world. But, one problem domain, possibly the most complex, demands action sooner rather than later: the user's perspective.

## The Problems from the User's Perspective

### The Breakdown of Family-based Care Giving

The user population of the elderly is anything but a homogenous population. Just a few of the differences easily seen in this group include 1) effects of varying ages which manifest different problems in small time periods, 2) large cultural differences, 3) large economic variance and 4) a variety of health issue combinations. These factors, and others, make it quite difficult to design technologies and protocols that will serve large groups of people. Basically, it is considered a basic axiom in Human Machine Interface that we can not build “one size fits all” solutions. This means a high degree of custom tailoring in the creation of tools to help the elderly do what they want most to do – “age in place.”

The “ageing in place” concept [3] usually means 1) living in the home you have occupied over a period of time, 2) not moving to a different neighborhood, city or state, 3) maintaining a cadre of old friends, 4) maintaining a relationship with traditional medical care providers and, 5) being close to other family members. These, and other difficult issues, exacerbate the problem of care supplied in the user’s comfort zone.

The demographics of life in the industrialized world have changed dramatically in the past fifty years. Traditionally, elder care was provided primarily by the women of the family, but this has changed dramatically. The stay-at-home mother/daughter/caregiver is an artifact of the past. Women are working outside of the home in greater numbers than ever before, making them unavailable in their traditional role as caregiver.

Other factors in the decline in family care giving, include 1) the high divorce rates in industrialized nations, which tend to make the traditional family structure unable to provide care to the elderly, and 2) the tremendous mobility in modern society. Instead of having the family unit living in close geographical proximity, modern life finds families spread across geographical areas, with little ability to provide care to their elderly members.

#### **Alternatives to Family-based Care giving**

What can replace the family care giver. Love and shared familial and cultural identity have been the hallmarks of the quality elderly care. With the loss of this type of care, it is critical that its replacement offer at least the most critical desire of the elderly, “aging in place.”

1. Remaining in their own homes
2. Living in familiar surroundings
3. Have the highest possible level of independence
4. Avoid the use of invasive health monitoring tools to the extent possible. The concept of sensors built into the ambient environment is an attractive method of continuing health monitoring.
5. The bottom line is simple: maintenance of personal dignity.

While, on the other hand, there is a generally negative attitude toward the notion of being “tied” to medical diagnostic equipment. These devices are considered:

1. Difficult to understand
2. Invasive of the user’s privacy
3. Another step on the path of losing self control, and with it, personal dignity.

These fears are based on several non-verbalized opinions by the user group which include:

1. The devices are designer-centric and don’t meet the needs of the non-expert user

2. The devices seem to have not been designed to work with other health monitoring devices and therefore will lead to the use of additional invasive devices
3. The devices seem to be quite costly to buy or lease and need constant maintenance.

In reality, the vast majority of home health monitoring devices have not been designed based on HCI and cognitive studies. The elderly require more user friendly devices than those generally available on the market. In a recent report from the European Institute for Prospective Studies [4], the authors made the following observation.

“In Europe, there are over 20,000 assistive devices on the market, but there is a significant market and supply failure.”

Added to the list of concerns about bad device interfaces and loss of independence, comes a set of even more basic issues. While these problems might be considered more serious in the United States<sup>1</sup> than in Europe, they still have a high level of legitimacy.

1. Privacy of the user's medical records.
2. The users lack of ability to negate the distribution of personal data.
3. The patient's ability to opt-out of the system at any time they might desire.

## **The Path Forward**

The benefits of aging in place are clear.

1. Aging in place better maintains and expands quality of life.
2. The costs associated with aging in place are considerably lower than institutional care.

Unfortunately, comprehensive systems to support the aging in place model are not yet in place and not yet affordable by the majority of the elderly community. While governmental data clearly point to a coming crisis, public financial support is slow in coming. It also seems clear that the market place has neither the interest or ability to solve the problems. Existing governmental and NGO efforts are not well funded or well coordinated.

The most attractive solution to this set of needs and is the development of a home with a high level of ambient intelligence which can monitor the user in a non-invasive manner, thereby facilitating the critical feeling of independence. Naturally, all of this must be done on an affordable basis. Currently, there are numerous “smart home” projects underway around the world.

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<sup>1</sup> Americans have a deep-seated distrust concerning their possible loss of individuality and privacy. Even, the concept of having a national identity card for all citizens, would be vigorously opposed by the majority of Americans from all political groups.

There are good reasons for the stake-holders in this issue to develop the ambient technologies to make aging a longer and more pleasant part of life. The benefits to each group, make the future solution more attractive. The groups being:

1. Ourselves
  - a. To support our aging family members in a time when direct family support is waning.
  - b. To guarantee a better aging process for ourselves, when the time comes.
2. Industry
  - a. New markets for technology products
  - b. Possible future reductions in retirement packages
3. Governments
  - a. Support for a rapidly growing and needy segment of our society
  - b. Fruits of the research and development project could “trickle down” to the rest of society
  - c. The possibility of reducing the cost of programs such as Medicare and Social Security.

## **Conclusions**

The problems are clear. We have a rapidly aging society with little help from the traditional family support group. The miracles of modern medicine have now given us a new set of health issues. With all good intentions, the medical community has given us dramatic improvements in our longevity, but has not given us the tools to better use and enjoy this extension in life expectancy.

Hollywood has painted a somewhat bleak picture of how to solve this problem. In movies such as “Logan’s Run,” [5] and “Soilent Green,” [6] we have seen the most draconian measures to solve the problems associated with aging. In “Cocoon,” [7] we were presented with a solution from outer space. While selling movies, these solutions don’t offer a reasonable alternative to a major effort, which includes users, industry and government.

## **References**

- [1] Long Range World Population Projections, the Department of Economic and Social Affairs, the United Nations Secretariat, 1998.
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[5] “Logan’s Run,” MGM 1976

[6] “Soilent Green,” MGM 1973

[7] “Cocoon,” Zanuck/Brown Productions, 1985